

## **GUAM -- 2001 Community PASS Grant**

### **Identified Problems with the Island's Long-Term Care System**

- Due to the lack of personal assistance services, persons with disabilities are inappropriately placed into treatment facilities, continue to remain in congregate settings, and experience prolonged waits for housing and supportive services.
- Guam is ineligible for funding under Supplemental Security Income Program.
- A cap on Guam's Medicaid federal expenditure strains Guam's ability to cover the cost of even the mandatory set of Medicaid services; optional services such as long-term care services and supports are not covered.
- There are no personal assistance services nor is there an infrastructure to develop a program.
- There is a serious shortage of supportive service options.
- Need to expand community capacity sufficiently to eliminate wait-lists, off-island placement, and inappropriate placement of persons with disabilities into treatment facilities.
- Division of Support Services for Individuals with Disabilities (DSSID) staff is unable to meet demand leading to low consumer satisfaction.

### **Perceived Strengths**

- The Individualized Budgeting Program will assist Guam towards the development of a system that is consumer responsive and flexible, and that empowers the individual to choose the supports and services
- The initial development of the Individualized Budgeting Program will explore a system where funding for services will be controlled by persons with disabilities in partnership with the Department of Integrated Services for Individuals with Disabilities (DISID)—DSSID.
- Persons with disabilities and their families will not be labeled and "fitted" into programs and services that the individual may not need; instead, services and supports will be tailored to meet the needs of the individual.

### **Primary Focus of Grant Activities**

- Develop Guam's Individualized Budgeting infrastructure for persons with significant disabilities.
- Implement an Individualized Budgeting Pilot Program.
- Enhance interagency and natural support partnerships by sustaining a network of valuable supports.
- Develop consumer-directed quality assurance/personal outcomes measures that promote consumer/family involvement.

## **Goals, Objectives, and Activities**

**Overall Goal.** To create a model demonstration Individualized Budgeting Program for individuals with significant disabilities to live in the most integrated community setting through the development of a flexible and consumer-directed service delivery system.

**Goal.** Develop and implement an Individualized Budgeting Program that includes the necessary infrastructure to meet the needs of, and provide choices for, persons with disabilities and their families.

### ***Objectives/Activities***

- DISID, in partnership with the Guma' Mami, Inc., and Catholic Social Services, will formalize its existing Individualized Budgeting/Self-Determination governing committee to ensure it includes more active involvement from persons with significant disabilities and families.
- Provide training to the governing committee in the area of Individualized Budgeting including periodic orientation sessions for new members with disabilities and families of the governing committee.
- Design and develop an Individualized Budgeting Program and the necessary infrastructure to provide for consumer-controlled services.
- Design and develop an urgent response system so that persons with disabilities and their families can receive information, advice, or short-term supports as part of the Individualized Budgeting Program.
- Assess the Individualized Budgeting Program in partnership with persons with significant disabilities and their families.

**Goal.** Develop a data system to track individual budgets and expenses under consumer-directed systems, to conduct ongoing needs assessments of the number of persons with disabilities in need of personal assistance services.

### ***Objectives/Activities***

- Develop a quality management system to assess personal outcome measures.
- Design a universal screening and tracking database and form.
- Develop a database workgroup comprising persons with disabilities and their families, local businesses, governmental agencies, and other service providers who will provide feedback towards the development of the database infrastructure.
- Design and develop a data management system.

**Goal.** Promote and facilitate strong cross program/natural support partnerships to optimize funding sources, and identify other creative funding mechanisms towards the creation of the Individualized Budgeting Program.

### ***Objectives/Activities***

- Develop a Creative Funding Task Force to identify and research various funding alternatives and mechanisms developing a comprehensive consumer-directed service delivery system.

- Increase and promote interagency coordination among state agencies, nonprofit providers, various local businesses, and volunteer groups to train persons with disabilities and their families, utilizing community outreach approaches.
- Conduct an island-wide symposium regarding the impact of consumer-controlled services and the impact of Individualized Budgeting for persons with disabilities and their families.

### **Key Activities and Products**

- Pilot and implement the Individualized Budgeting Program.
- Develop a final report documenting Guam's progress towards consumer-directed systems.
- Develop an emergency response system for the Individualized Budgeting Program.
- Develop consumer-directed quality assurance/personal outcomes measures that promote consumer/family involvement.
- Develop a Creative Funding Task Force to identify and research various funding alternatives and mechanisms for developing a comprehensive consumer-directed service delivery system.

### **Consumer Partners and Consumer Involvement in Planning Activities**

Persons with disabilities are non-voting members of the Individualized Budgeting/Self-determination Committee, which is also comprised of governmental entities and non-profit providers.

### **Consumer Partners and Consumer Involvement in Implementation Activities**

Persons with disabilities are non-voting members of the Individualized Budgeting/Self-Determination Committee, which also includes governmental entities and non-profit providers.

### **Public Partners**

- Department of Revenue and Taxation.
- Department of Mental Health and Substance Abuse.
- Department of Public Health and Social Services.
- Department of Education.
- Department of Labor.
- Department of Administration.
- Guam Housing and Urban Renewal Authority.
- Office of the Public Guardian.

### **Private Partners and Subcontractors**

- Non-profit providers.
- Guma' Mami, Inc.
- Catholic Social Services.
- Guam Center for Excellence in Developmental Disabilities Education, Research, and Service (Guam CEDDERS/UAP).
- Disability Law Center—Protection and Advocacy for Guam.

## **Public and Private Partnership Development/Involvement in the Planning Phase**

### **Public Partners**

A series of training initiatives in “flexible funding/self-determination” as well as meetings with local senators and policymakers in January 2001 contributed to a dialogue among service providers, community leaders, and persons with disabilities to shift from a service-controlled model of care to a consumer-controlled model. In February 2001, after discussions with Jan Nesbit, Ph.D., Guam DDC, and Guam CEEDERS, Senator Lou Leon Guerrero undertook the initiative to form the Individualized Budgeting/Self-Determination Committee.

### **Private Partners**

A large meeting took place with representation from persons with mental illness, persons with cognitive and other developmental disabilities, families, Guam Legal Services, representation from the Department of Mental Health and Substance Abuse, representation from Disability Law Center—Protection and Advocacy for Guam, Guam Developmental Disabilities Council, Department of Public Health and Social Services, Catholic Social Services to obtain recommendations for the proposal.

## **Public and Private Partnership Development/Involvement in Implementation**

### **Public Partners**

- Department of Revenue and Taxation (Provide guidance/information regarding taxes if individuals with disabilities choose to hire personal care attendance).
- Department of Mental Health and Substance Abuse (Serve as a resource for the development of the urgent response system; review drafts of the Individualized Budget Manual prior to implementation).
- Department of Public Health and Social Services (Database System Development; review drafts of the Individualized Budget Manual).
- Department of Education (Refer participants to the pilot project; share recommendations regarding the development of the database system; review draft of the Individualized Budget Manual).
- Department of Labor (Provide information/training regarding labor laws relevant to personal care attendants).
- Department of Administration (Provide information regarding processing of checks and provide guidance as to how money should be disbursed).
- Guam Housing and Urban Renewal Authority (Provide information regarding the Fair Housing Act, information regarding housing subsidies and benefits for housing for persons with disabilities).
- Office of the Public Guardian (review drafts of the Individualized Budget Manual).

**Private Partners**

- Catholic Social Services (Urgent Response System; review drafts of the Individualized Budget Manual).
- Other nonprofit organizations such as the Salvation Army, the Disability Law Center—Protection and Advocacy for Guam will review drafts of the Individualized Budget Manual.
- Guam Center for Excellence in Developmental Disabilities Education, Research and Service (Guam CEDDERS/UAP) (Training Module Development/Impact Study).
- Guam Developmental Disabilities Council will provide recommendations for the development of the Territorial Agenda/Public Policy initiatives regarding the need for Personal Assistance Services. They will also review a draft of the Individualized Budget Manual.

**Oversight/Advisory Committee**

The Advisory Committee will assist in the development and implementation of an Individualized Budgeting Program; provide direction and guidance related to the database infrastructure; and collaborate with project staff in identifying support and coordinating activities as needed.

**Formative Learning and Evaluation Activities**

- A process evaluation will assess project activities and collaborative group activities during the development and consensus building or formative stage of the grant.
- A summative evaluation will focus on the extent to which the project was successful in providing the climate for consensus building and eventual achievement of outcomes specified by the collaborative groups.

**Evidence of Enduring Change/Sustainability**

The effort will aid in the development of an infrastructure that is flexible and responsive to the needs and choices of persons with disabilities and their families, and will continue after the grant ends.

**Geographic Focus**

Islandwide.